

Melissa Weipert

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Health Policy

From: ksitarz79 <ksitarz79@yahoo.com>
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To: Melissa Weipert
Subject: House Bill 4584

Our diagnosis story is one of incomplete diagnosis and fear. We were fortunate enough not to get the doom and gloom diagnosis that so many others have received, but mostly because they could not figure out what was going on with my daughter. Although we did not have a formal diagnosis, termination was offered. We declined, and it wasn't brought up again.

I spent the rest of my pregnancy worrying about what was going on with my unborn child. I researched every possibility they suggested, and then some. Despite being as prepared as I could be, things were still very hard. My daughter was born with a myelomeningocele. She required multiple specialists, regular doctor visits, and two surgeries in her first 3 months of life.

I was scared, and I didn't know who to talk to. I found a group on Babycenter called "Spina Bifida Kids". It is a great question answer forum. I soaked up as much information as I could.

It was on Babycenter that I met another spina bifida mom from Michigan. She got me in contact with the spina bifida community via Facebook. Facebook allowed me to connect with another mom that was in the NICU at the same time I was. She has a son with spina bifida. She introduced me to a group of wonderful women and men raising their child with spina bifida.

These people are my tribe. Things can still be stressful, but having these people in my life has made things so much more bearable. I talk to these people on a regular, almost daily basis. They get my life! We ask questions, celebrate accomplishments, share disappointments, and plan vacations together. Second annual camping weekend is coming up!

I wish I had been connected with these people immediately. Navigating the first few months of my daughters care by myself was terrifying. Having these women to vent to, and to ask questions of, would have made a substantial impact on my pregnancy, birth, and newborn experience. I certainly would have benefited from receiving information about the spina bifida community along with my daughters diagnosis. Some moms are lucky enough to be given that information immediately. Unfortunately, I was not. I worry about the families that still have not found support, because they do not know it exists.

Thank you for your time,
Kourtne Sitarz